IN THE UNITED STATES DISTRICT COURT
FOR THE EASTERN DISTRICT OF TEXAS
TYLER DIVISION

ALBERTO N., by his parents and next friends, Mr. and Mrs. N.; ALICE F. by her next friend, Ms. K; KEYAIRA R.-D., by her parent and next friend, Ms. D.; KAITLYN C., by her parent and next friend, Ms. C; AARON D., by his parent and next friend, Ms. D; ANDREW M., by his parent and next friend, Ms. M.; EVAN W., by his parents and next friends, Mr. and Mrs. W.; CHELSEA C., by her parent and next friend, Ms. C.; on behalf of themselves and others similarly situated,	§	
Plaintiffs,	§	
V.	§	CASE NO. 6:99CV459
DON A. GILBERT, in his official capacity as Commissioner of the Texas Health and Human Services Commission; WILLIAM R. ARCHER, III, M.D., in his official capacity as Commissioner of the Texas Department of Health; and ERIC M. BOST, in his official capacity as Commissioner of the Texas Department of Human Services,	§	CLASS ACTION
Defendants.	§	

FIRST AMENDED COMPLAINT

I. INTRODUCTION

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1. This lawsuit is filed on behalf of Medicaid beneficiaries under the age of twenty-one who have disabilities and chronic health conditions and who are unable to obtain medically necessary in-home health care services. Plaintiffs are entitled to these medical services under the Early and Periodic Screening, Diagnosis, and Treatment ("EPSDT") program for Medicaid eligible individuals under the age of twenty-one.

2. Defendants, the Texas Health and Human Services Commission ("THHSC"), the Texas Department of Health ("TDH"), and the Texas Department of Human Services ("TDHS") (referred to collectively as "Texas Medicaid") have adopted policies and engaged in practices which have resulted in the systematic denial of in-home nursing services, medical equipment, and other support services for these children and young adults, in violation of the Medicaid Act, the Americans with Disabilities Act ("ADA"), and the Due Process Clause of the Fourteenth Amendment to the United States Constitution.

3. Plaintiffs seek declaratory and injunctive relief to end Defendants' unlawful policies and practices.

4. Plaintiffs sue on behalf of themselves and the class of all similarly situated Medicaid eligible individuals under the age of twenty-one who have been, or will be, unlawfully denied medically necessary in-home services from Texas Medicaid.

II. JURISDICTION AND VENUE

5. This Court has jurisdiction over this action pursuant to 28 U.S.C. §§ 1331 and 1343 (3) and (4).

6. This action is authorized by 42 U.S.C. § 12133 and by 28 U.S.C.§§ 2201 and 2202.

7. Venue is appropriate in the United States District Court for the Eastern District pursuant to 28 U.S.C. § 1391(b) because part of the events or omissions giving rise to these claims occurred in this District.

III. PARTIES

8. Plaintiff, Alberto N. is two-years-old and resides in McAllen, Hidalgo County, Texas. Alberto N. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

9. Plaintiff, Alice F. is two-years-old and resides in El Paso, El Paso County, Texas. Alice F. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

10.. Plaintiff, Keyaira R.-D. is five-years-old and resides in Austin, Travis County, Texas. Keyaira R.-D. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

11. Plaintiff, Kaitlyn C. is nine-years-old and resides in Austin, Travis County, Texas. Kaitlyn C. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

12. Plaintiff, Aaron D. is ten-years-old and resides in Hallsville, Harrison County, Texas. Aaron D. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

13. Plaintiff, Andrew M. is eleven-years-old and lives in Tyler, Smith County, Texas. Andrew M. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. §12131(2).

14. Plaintiff, Evan W. is eleven-years-old and resides in Houston, Harris County, Texas. Evan W. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

15. Plaintiff Chelsea C. is fourteen-years-old and resides in Lewisville, Denton County, Texas. Chelsea C. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

16. Defendant, DON GILBERT, is the Commissioner of THHSC, the single state agency responsible for the administration of the Texas Medicaid program. In his capacity as Commissioner of the single state agency for Texas Medicaid, he is ultimately responsible for the operation of the Texas Medicaid program in accordance with the Medicaid Act, 42 U.S.C. § 1396 *et seq*. As Commissioner of the single state agency for Medicaid, Commissioner Gilbert may delegate the daily administration of Texas Medicaid to various state agencies. Don Gilbert is sued in his official capacity.

17. Defendant, WILLIAM R. ARCHER, III, M.D., is the Commissioner of the Texas Department of Health and has been delegated the administration of various parts of the Texas Medicaid program, including health care services for Medicaid beneficiaries under twenty-one years of age. Dr. Archer is sued in his official capacity.

18. Defendant, ERIC M. BOST, is the Commissioner of the Texas Department of Human Services and has been delegated the administration of various parts of the Texas Medicaid program, including the Primary Home Care Services benefit. Eric Bost is sued in his official capacity.

19. THHSC, TDH, and TDHS, the state agencies administered by Don Gilbert, Dr. Archer and Eric Bost, are responsible for the policies challenged by this lawsuit and are public entities within the meaning of the Americans with Disabilities Act.

IV. CLASS ACTION ALLEGATIONS

20. Named Plaintiffs bring this action on behalf of themselves, and pursuant to FED. R. CIV. P. 23(a) and 23(b), on behalf of a class defined as: all similarly situated Medicaid eligible individuals under the age of twenty-one in Texas who have been, or will be, unlawfully denied medically necessary services from Texas Medicaid.

21. The requirements of FED. R. CIV. P. 23 are met in that the class is so numerous that joining all members is impracticable. Approximately 1.4 million children and adolescents under the age of twenty-one in Texas are eligible for Medicaid services. According to TDH, approximately 19,500 Medicaid eligible children and youth require daily, ongoing, medical treatments and monitoring.

22. The requirements of FED. R. CIV. P. 23 are met in that all of the members of the class share common issues of law and fact. Plaintiffs are eligible for EPSDT services, but have been denied those services by Defendants. Defendants subject Plaintiffs and the

class they represent to the same unlawful medical necessity determination process when they deny EPSDT services.

23. The requirements of FED. R. CIV. P. 23 are met in that the named Plaintiffs' claims that Defendants' failure to provide medical services in violation of the Medicaid Act, the ADA, and the United States Constitution are typical of the claims of the class they represent.

24. The requirements of FED. R. CIV. P. 23 are met in that named Plaintiffs will fairly and adequately protect the interests of the class they represent.

25. The requirements of FED. R. CIV. P. 23 are met in that named Plaintiffs have no interest antagonistic to or in conflict with the interests of the class.

26. The requirements of FED. R. CIV. P. 23 are met in that Plaintiffs are represented by experienced counsel who will adequately represent the interests of the class. Counsel for Plaintiffs, Maureen O'Connell, Maryann Overath and Melissa Uram, are employed by Advocacy, Incorporated, the designated protection and advocacy agency that provides legal services to persons with disabilities.

27. Defendants have acted and refused to act and continue to do so on grounds generally applicable to the class the Plaintiffs represent, thereby rendering appropriate declaratory and injunctive relief for the class as a whole.

V. STATEMENT OF FACTS

The Medicaid Program

28. In 1965, Congress enacted Title XIX of the Social Security Act, 42 U.S.C. § 1396 *et seq.* ("the Medicaid Act"), establishing the Medicaid program, a voluntary, cooperative, federal-state program to provide necessary medical services to eligible beneficiaries. Texas elected to participate in the Medicaid program in 1967.

29. States that participate in the Medicaid program receive matching funds called federal financial participation ("FFP"). To receive FFP, states must adhere to the federal requirements found in the Medicaid Act and its implementing regulations. 42 U.S.C. § 1396a *et seq.*; 42 C.F.R. §§ 430 *et seq.*

30. Pursuant to these requirements, Texas has developed a state plan which identifies the broad categories of required and optional medical services which are part of the Texas Medicaid program. Under the provisions of the Act, Texas's Medicaid plan must provide the following required services: inpatient and outpatient hospital services; other laboratory and x-rays; nursing facility services; home health services (including durable medical equipment); early and periodic screening, diagnostic and treatment services ("EPSDT") for beneficiaries under age twenty-one; physicians services; nurse-midwife services; and certified pediatric and nurse practitioner services. 42 U.S.C. § 1396a; 42 C.F.R.§ 440.210.

31. In addition to the required services that must be included in the Medicaid state plan, Texas Medicaid can choose from a list of over thirty (30) optional services to include

in its state plan. Examples of these optional services include: private duty nursing services; dental services; physical therapy; occupational therapy; services for individuals with speech, hearing and language disorders; case management services; and personal care services. 42 U.S.C. § 1396(d)(a); 42 C.F.R. § 440. *et seq.*

32. To further comply with the Medicaid Act, Texas Medicaid must set reasonable standards in the operation of its program. 42 U.S.C. § 1396a(a)(17).

33. Moreover, each service within the Medicaid state plan must be sufficient in amount, duration, and scope to reasonably achieve its purpose and services may not be arbitrarily denied or reduced in amount, duration, and scope because of the diagnosis, type of illness, or condition of an eligible beneficiary. 42 C.F.R. §§ 440.230(b) and (c).

34. Texas Medicaid must also inform Medicaid beneficiaries of the available health care and treatment available under the program. 42 U.S.C. § 1396(a)(43)(A).

Medicaid Services for Beneficiaries under the Age of Twenty-one

35. In 1990, the Medicaid Act was amended to expand the scope of services available under the EPSDT benefit, a required category of service for beneficiaries under the age of twenty-one. This amendment requires Texas Medicaid to provide "such other necessary health care, diagnostic services, treatment, . . . to correct or ameliorate defects and physical and mental illnesses and conditions . . ." 42 U.S.C. § 1396d(r)(5).

36. Under this expanded EPSDT benefit, called Texas Health Steps Comprehensive Care Program ("CCP"), Texas Medicaid is required to provide all optional and required categories of service under the Medicaid Act to beneficiaries under the age of

twenty-one when such treatment or service is found to be medically necessary. 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(r)(5).

37. Texas Medicaid describes CCP services as the set of services mandated by federal law to provide all medically necessary, appropriate, and federally allowable services to children, including those services that are not covered under the state's Medicaid plan for Medicaid beneficiaries 21 years-of-age or older.

38. Texas Medicaid defines the term "medical necessity," in relevant part, as "the need for medical services in an amount and frequency sufficient, according to accepted standards of medical practice, to preserve health and life and to prevent future impairment." 25 TAC § 43.25.

39. To obtain CCP services, the Medicaid beneficiary's treating physician must prescribe the service and attest to the beneficiary's medical necessity for the service.

40. Medicaid beneficiaries obtain CCP services, such as private duty nursing, speech therapy, occupational therapy, physical therapy and medical equipment, by submitting a request for prior authorization to Texas Medicaid, that includes the treating physician's statement that the service is medically necessary for the beneficiary.

41. Texas Medicaid contracts with a private health insuring organization, National Heritage Insurance Company ("NHIC") to administer part of the Medicaid program, including making determinations as to whether Medicaid applicants or participants meet the medical necessity criteria for Medicaid services.

42. Texas Medicaid is responsible for all Medicaid coverage and medical necessity determinations made by NHIC.

43. These determinations must be made in a timely manner as EPSDT treatment services must be provided in a timely fashion, with an outside limit of six (6) months from the date of the request. 42 C.F.R. § 441.56(e).

44. Texas Medicaid must also "make available a variety of individual and group providers qualified and willing to provide EPSDT services." 42 C.F.R. § 441.61(b).

The Texas Medicaid Home and Community-Based Waiver Program for Medicaid Beneficiaries Under the Age of 21

45. In addition to the services available through the EPSDT benefit, approximately 816 Medicaid beneficiaries receive supplemental health services through the Medically Dependent Children's Program ("MDCP"). This program is a Medicaid Home and Community-Based waiver program designed to provide home and community-based services to Medicaid beneficiaries under age twenty-one as an alternative to institutionalization. 42 U.S.C. § 1396n(c)(2), 25 TAC § 34.1 *et. seq.*

46. In order to operate a Home and Community-Based waiver consistent with the requirements of the Medicaid Act, 42 U.S.C. § 1396n(c)(2)(D), Texas Medicaid must assure that the average per capita expenditure for waiver participants does not exceed 100 percent of the average per capita expenditure that the state estimates would be made for expenditures under the state plan for such individuals if the waiver was not in effect.

47. To be eligible for MDCP, the beneficiary must meet the medical necessity criteria for nursing facility care.

48. Each MDCP participant has an Individual Plan of Care that describes the array of in-home and community services to be provided to the participant.

49. The cost of the Individual Plan of Care cannot exceed the cost allowance assigned to the participant.

50. The cost allowance is the maximum dollar amount available for reimbursement for an MDCP participant's approved waiver services. The cost allowance is equal to 63 percent of the annual reimbursement rate that Texas Medicaid would pay for skilled nursing facility care as of September 1, 1996.

51. Texas Medicaid determines the reimbursement rate for skilled nursing facility care by computing the participant's Texas Index for Level of Effort ("TILE") designation. The TILE designation is based on the intensity of the care needs of individuals in Texas nursing facilities.

52. Texas Medicaid will pay 100 percent of the TILE reimbursement rate for services provided to a Medicaid beneficiary in a nursing facility; however, it will only pay 63 percent of the TILE rate for services provided to the beneficiary through the MDCP program in the home and community.

53. Prior to 1997, the array of services available under MDCP included private duty nursing services. However, in September 1997, Texas Medicaid eliminated private duty nursing services as benefit of MDCP because this service must be made available to all Medicaid beneficiaries through the CCP and waiver services are designed to supplement, not replace, state plan services.

Due Process Protections for Medicaid Beneficiaries

54. The Medicaid Act and federal regulations promulgated pursuant to the Medicaid Act require Texas Medicaid to inform Medicaid beneficiaries in writing of their right to request a fair hearing if their claim for benefits is reduced, denied, terminated or not acted upon with reasonable promptness. 42 U.S.C. § 1396a(a)(3); 42 C.F.R. § 431.200 *et seq.*

55. Notice of a reduction, denial or termination of benefits or of a claim that is not acted upon with reasonable promptness must include: a statement of what action Texas Medicaid intends to take; the reasons for the intended action; the specific regulations that support, or the change in Federal or State law that require, the action; an explanation of the individual's right to request an evidentiary hearing, if one is available, or a State agency hearing; in cases of an action based on a change in law, the circumstances under which a hearing will be granted; and an explanation of the circumstances under which Medicaid is continued if a hearing is requested. 42 C.F.R. § 431.210.

56. Texas Medicaid must mail the notice at least ten days before the date of action. 42 C.F.R. § 431.211.

Texas Medicaid's Failure to Comply with the Medicaid Act

57. Although Texas Medicaid acknowledges that it must provide all medically necessary services to Medicaid beneficiaries under the age of twenty-one, Defendants, through NHIC, routinely deny, terminate and reduce in-home nursing, personal assistance

services, and medical equipment to Medicaid beneficiaries under the age of twenty-one in disregard of the opinion of the treating professionals.

58. Plaintiffs, as described below, have all submitted requests for prior authorization for in-home Medicaid services. The requests included statements by Plaintiffs' treating physicians that the services are medically necessary. The need for medical services met Texas Medicaid's definition of medical necessity, in that the services were prescribed "in an amount and frequency sufficient, according to accepted standards of medical practice, to preserve health and life and to prevent future impairment."

59. Texas Medicaid denied these requests for in-home Medicaid services without evaluation of Plaintiffs and despite the opinions of the treating physicians that the services are medically necessary.

60. Not only does Texas Medicaid fail to defer to the treating physician's opinion regarding medical necessity, it fails to use its own definition of medical necessity when over-ruling the treating physician and, instead, makes arbitrary determinations with no reference to medical standards.

61. Texas Medicaid reduces and terminates medical services being provided to Medicaid beneficiaries even though the beneficiary's medical condition has not changed and, therefore, no reduction or termination of services is warranted.

62. Additionally, Texas Medicaid denied requests by MDCP participants for CCP in-home nursing services despite previous assurances by MDCP administrators that MDCP

participants would be able to access private duty nursing services through CCP once these services were eliminated from the array of MDCP benefits.

63. After making decisions to deny, reduce, or terminate a service, Texas Medicaid frequently fails to provide notice to the Medicaid beneficiary regarding the denial, reduction, or termination of the service and the beneficiary's right to request a fair hearing to challenge the denial, reduction, or termination of the service.

64. Even when Texas Medicaid provides notice to the Medicaid beneficiary, the notice fails to state the reasons for the intended action, the specific regulations that support, or the change in Federal or State law that required the action, and fails to provide an explanation of the circumstances under which Medicaid is continued if a hearing is requested.

65. These notices often state only that the "documentation does not support the medical necessity" for the service. The notice fails to provide any explanation or reason as to why the documentation provided by the treating physician fails to support the medical necessity for the service; nor does it provide the criteria upon which the determination was made.

66. Without information regarding the basis upon which Texas Medicaid has denied, terminated, or reduced the requested service, Medicaid beneficiaries have no opportunity to successfully appeal the denial, termination, or reduction.

67. Texas Medicaid fails to provide notice to beneficiaries when it determines that a requested benefit is not covered within the Medicaid program. It sometimes provides

notice to the Medicaid provider; however, even then, the notice only states "not covered," and provides no other information regarding this determination.

68. Texas Medicaid does not provide beneficiaries an opportunity to request a fair hearing to challenge a determination that a benefit is not covered within the Medicaid program.

69. In sum, Texas Medicaid denies, reduces and terminates medical services, without evaluation of the beneficiaries, consultation with their physicians, and in direct contradiction to the recommendations of the beneficiaries' treating physicians, the beneficiaries' medical status, and its own definition of medical necessity. It subsequently fails to provide the beneficiaries with proper notice of the denial, reduction or termination of services and fails to provide beneficiaries with the opportunity to request a fair hearing to challenge the denial, reduction, or termination of services.

The Named Plaintiffs

Alberto N.

70. Alberto N. was born on January 21, 1997, and lives with his mother, father and four young siblings in McAllen, Texas. The Ns. left their home and family in Laredo, Texas, to move to McAllen in order to obtain medical services for Alberto.

71. Alberto was diagnosed with Spinal Muscular Atrophy-Werdnig Hoffmann type ("SMA"), at the age of four months after experiencing repeated respiratory failure. SMA is a neurological disease that causes rapid and severe degeneration of the cells in the nervous

system. These cells are responsible for sending signals to the muscles of the body, including the muscles used to breath.

72. As a result of the degeneration of these cells, Alberto has paralysis and cannot breath independently. Instead, Alberto's breathing is assisted with a ventilator. The ventilator "breathes" for Alberto through a tube that has been placed in his windpipe, called a tracheotomy.

73. Alberto spent most of the first five months of his life in the hospital. He was discharged from the hospital in June 1997, and went home with the support of the ventilator.

74. Alberto requires the use of the ventilator twenty-four hours per day. Alberto's tracheotomy tube must be suctioned every five-to-ten minutes so that he can continue breathing. Because Alberto must be monitored and suctioned twenty-four hours per day, he can not be left unattended by trained professionals.

75. As a result of the SMA, Alberto has many other medical needs including the need to be fed through a gastrostomy tube ("g-tube") in his stomach. He must be fed through the g-tube fifteen times per day.

76. Alberto requires a number of medications that are administered through injection, the g-tube or through a nebulizer, as well as medications applied to his skin to address skin breakdown caused by his inability to change positions independently.

77. Alberto's physician, Humberto Hidalgo, M.D., board certified pediatric pulmonologist, and the nursing agency that provides Alberto's nursing services, MCH Services Pediatric Nursing Specialists, have written detailed plans of medical treatment for

Alberto, that describe Alberto's need for the following skilled care services: oral, nasal and tracheotomy suctioning every five-to-ten minutes; hyperventilating Alberto, if necessary, after suctioning; assessment and monitoring of cardiopulmonary status; assessment and evaluation of lung sounds and breathing patterns; provision of oxygen for respiratory distress; assessment and monitoring of oxygen levels using a pulse oximeter; monitoring ventilator settings; g-tube feeding; administration of medication; assessment for signs and symptoms of dehydration; monitoring of bowel movements; assessment, monitoring and treatment of skin breakdown; positioning Alberto to diminish skin breakdown; assessment and monitoring of neurological status; hanging the tracheotomy ties daily; and, changing the tracheotomy tube as needed, but at least every two weeks. The plan also requires that Alberto be provided assistance with all activities of daily living including: bathing, diapering, oral hygiene, and gentle range of motion exercises.

78. At the age of five-months, Alberto was discharged from the hospital and Texas Medicaid provided him with 24 hours per day of nursing services for fifteen (15) days. Texas Medicaid then reduced the number of nursing services hours to 22 hours per day and provided those services for ten (10) weeks. Subsequently, Texas Medicaid has reduced the nursing services hours by one to two hours, every three months. None of these reductions have been based upon the professional opinion of Alberto's treating physician, Dr. Hidalgo, or the nursing agency, MCH.

79. On March 5, 1998, Dr. Hidalgo submitted a request to Texas Medicaid for prior authorization of 18 hours per day of nursing services for Alberto. Texas Medicaid, through

NHIC, denied the request for 18 hours per day but authorized the provision of 16 hours of nursing services per day for the period of March 3, 1998, through April 26, 1998, 15 hours of nursing services per day for the period April 27, 1998, through May 26, 1998, and 14 hours of nursing services per day for the period May 27, 1998, through June 26, 1998.

80. Texas Medicaid reduced the nursing services, without evaluation of Alberto, consultation with his physician, and in direct contradiction to the recommendations of Alberto's treating physician and nurses.

81. Ms. N. requested a fair hearing to appeal the reduction and a hearing was held on May 14, 1998.

82. The TDH hearing examiner sustained Texas Medicaid's decision to reduce the nursing services. The decision does not defer to, or even mention, the opinion of Alberto's treating physician. Despite the plan of treatment confirming Alberto's medical need for nursing services, the hearing examiner found that Alberto has some skilled nursing needs but that most of his needs are custodial or respite.

83. On August 31, 1998, MCH Services received notice from NHIC that Texas Medicaid denied Dr. Hidalgo's prior authorization request to provide nursing services to Alberto for 16 hours per day from August 17, 1998 to October 10, 1998. The denial stated that the "doc does not support medical necessity."

84. Ms. N. did not receive notice of the denial until after September 23, 1998. The notice stated that the "medical information received does not support the number of hours being requested." It failed to provide any other information about the basis for the denial of

nursing services, it did not describe the federal regulations that support the denial of services and it failed to provide an explanation of the circumstances under which the services are continued if a hearing is requested.

85. Texas Medicaid approved 14 hours per day of nursing services and informed the nursing agency, during telephone conversations about the prior authorization request, that it planned to reduce the 14 hours per day to ten hours per day beginning September 16, 1998.

86. Texas Medicaid, through NHIC, denied the request to provide 16 hours per day of nursing services, without evaluation of Alberto, consultation with his physicians, and in direct contradiction to the recommendations of Alberto's treating physician and nurses.

87. Both Dr. Hidalgo and MCH Services submitted additional letters to NHIC describing Alberto's medical necessity for 18-20 hours of nursing services per day, not to be reduced below 16 hours.

88. Texas Medicaid has refused to provide the 18-20 hours per day of nursing services prescribed by Dr. Hidalgo. Alberto currently receives 14 hours per day of nursing service and, upon information and belief, Texas Medicaid will continue to reduce those hours despite the treating physician's opinion regarding Alberto's medical need for nursing services.

89. Nursing services are provided to Alberto during the hours of 4 p.m. to 6 a.m. At 6 a.m., Ms. N. assumes the responsibility for providing Alberto with all of his nursing services, although Ms. N. is not a nurse and has had no formal medical training.

90. In order to provide Alberto with the medical support services he needs, including suctioning, Ms. N. cannot leave his bedside for more than several minutes at a time.

91. Ms. N. has four other children: two sons, ages two and four, and two daughters, ages eight and ten. The tremendous amount of medical care that she must provide to Alberto impacts her ability to care for her other children.

92. Ms. N. has also applied for Primary Home Care Services for Alberto. Primary Home Care Services is a Medicaid benefit that provides personal assistance services, and is administered by the Texas Department of Human Services ("TDHS").

93. In June 1998, TDHS denied the request for primary home care services. The notice stated that the services were "denied due to lack of functional need." No other information describing the basis for the denial was provided in the notice.

Alice F.

94. Alice F. was born on April 12, 1997. Shortly after her birth, she was placed in the permanent managing conservatorship of the Texas Department of Protective and Regulatory Services. Placement with the Ks, a foster family in El Paso, Texas, was authorized on August 1, 1997, and since that time she has remained in their home.

95. Alice was born prematurely and was immediately diagnosed with Trisomy 18, a chromosomal condition associated with the presence of an extra number 18 chromosome. The extra chromosome causes organ malformations and in Alice's case, has resulted in a

congenital heart defect, a gastro-intestinal disorder, developmental delay and partial blindness.

96. Alice's heart defect, Tetralogy of Fallot, is the most disabling aspect of her Trisomy 18. The condition has caused a hole in the wall separating the right and left ventricles, a narrowing of the pulmonary valve, a displaced aorta, and a thickening of the left ventricle wall. Because of these impairments, blood flow to the lungs is obstructed and insufficiently oxygenated blood is pumped through her body. Oxygen, therefore, must be administered to Alice on a twenty-four hour basis and monitored closely throughout that time. As a result, Alice is at risk of sudden death.

97. Trisomy 18 also affects Alice's esophagus. She has been diagnosed with Esophageal Atresia which is a narrowing or obstruction of the esophagus. This condition requires that she be fed through a gastrostomy tube ("g-tube") in her stomach. The feeding process must be initiated every four hours and each feeding lasts approximately one hour. Feedings are often difficult because Alice's esophagus causes frequent vomiting. Additionally, all medications must be administered through the g-tube.

98. Alice's heart condition also contributes to sleep apnea, an abrupt cessation of breathing during sleep. As a result, she has very irregular sleeping patterns and never sleeps longer than two hours at a time. Oxygen must be constantly monitored while Alice is both asleep and awake by checking for cyanosis, a blueing of the skin due to decreased oxygen levels in the blood. When cyanotic spells occur, oxygen must be increased to resupply the

blood with oxygen. However, a severe cessation of breathing is a persistent possibility and Alice's caregiver must be trained in infant CPR to appropriately respond to this threat.

99. Alice has been in the care of two physicians since her initial release from the hospital, Dr. John Guggeddah and, currently, Dr. Jagdish Patel of the Pediatric Health Center in El Paso, Texas. Two nursing agencies have provided her skilled nursing services, Visiting Nurse Association of El Paso ("VNA") and, currently, Pasos Home Health. These medical professionals have developed a plan of care which itemizes Alice's specific care needs.

100. Alice's current daily skilled nursing care needs are listed in that plan as follows: assessment of cardiovascular system by monitoring heart sounds, peripheral circulation, and pulse; assessment of respiratory status by listening to lung sounds and analyzing cough/sputem; assessment of gastrointestinal status by listening to bowel sounds and monitoring nutrition and elimination; monitoring skin breakdown; administration of medication every four, six, and twelve hours; assessment of g-tube placement and signs or symptoms of complications; assessment of hydration status; assessment of home safety measures; assessment of Alice's comfort and pain status; cleaning of g-tube site; administration of inhalation therapy; performance of chest physiotherapy ("CPT") every four hours; administration of saline drops to nose; provision of verbal and tactile stimulation throughout shift; instruction to caregiver on disease process, treatment, management, and appropriate interventions.

101. Upon Alice's placement in her foster home, Texas Medicaid provided Alice with eight hours per day (56 hours per week) of skilled nursing services to administer Alice's plan of care. The remainder of the day and evening Alice was cared for by her foster mother, Ms. K. Ms. K. is not a nurse but has had some medical training in Mexico.

102. Texas Medicaid continued to provide 56 hours of nursing services per week until October 1998. At that time, Alice's nursing services provider changed from VNA to Pasos Home Health. Pasos Home Health sought prior authorization to provide 56 hours per week of nursing services to Alice for the period of October 16, 1998 through December 16, 1998. Pasos Home Health received notice that prior authorization for 56 hours a week of private duty nursing was denied.

103. Initially, Texas Medicaid, through NHIC, denied the request because it mistakenly understood that VNA was authorized to provide services and that any additional authorizations would result in duplication of Medicaid services. Pasos Home Heath provided Texas Medicaid with documentation indicating that it is the sole home health agency caring for Alice but Texas Medicaid denied the request for prior authorization on December 3, 1998. Ms. K. did not receive a copy of this denial.

104. Pasos Home Health secured additional documentation that Alice's foster family and caregiver wished to change providers from VNA to Pasos Home Health. They submitted this letter along with the previously submitted paperwork requesting prior authorization on December 3, 1998. The application was denied for the second time. This denial, dated December 9,1999, stated, "Documentation submitted does not support medical necessity for

hourly nursing. Caregiver is trained. Documentation does not indicate client is unstable. CCP does not authorize hours for respite care." Mrs. K. did not receive a copy of this denial.

105. Texas Medicaid, through NHIC, denied the nursing services, without evaluation of Alice, consultation with her physicians, and in direct contradiction to the recommendations of Alice's treating physician and nurses.

106. Throughout this time period, Pasos Home Health continued to provide Alice with 56 hours of nursing services per week and submitted an appeal of the denial, seeking payment for the services. Texas Medicaid responded to the Pasos Home Health's appeal on March 29, 1999, by authorizing payment for skilled nursing services for 40 hours per week from October 16, 1998 through November 15, 1998, and 20 hours per week from November 16, 1998 through December 15, 1998. After that date, Alice was to be discharged from all services.

107. The approval for these hours, however, has never resulted in payment to Pasos Home Health for services rendered from October through December. Approval for these hours was authorized on March 29, 1999, and, as a result, Texas Medicaid refuses to process the payment claims submitted by Pasos Home Health because they were submitted after the 95-day billing period.

108. On the same date that Pasos Home Heath submitted its prior authorization application to Texas Medicaid for the period of October 16, 1999 through December 15, 1999, it submitted two additional requests for prior authorization of Alice's care. These requests, for the periods of December 16, 1999 through February 15, 1999, and February 16,

1999 through April 15, 1999, resulted in March 29, 1999, denials by Texas Medicaid. Each denial stated, "Documentation does not support medical necessity for hourly nursing." Mrs. K. did not receive copies of these denials.

109. On April 27, 1999, the billing agent at Pasos Home Health was called by a representative of Texas Medicaid who urged her to resubmit the requests for prior authorization for the period of February 16, 1999 through April 15, 1999. Pasos Home Health followed this suggestion and submitted a request for 56 hours per week of skilled nursing services for Alice on April 27, 1999, April 30, 1999, and May 4, 1999. The requests included an additional letter from Alice's caseworker at the Texas Department of Protective and Regulatory Services, which stressed the need for approval of a full 56 hours of skilled nursing, as well as a court order from an El Paso County District Court.

110. Citing omissions in the application paperwork, Texas Medicaid denied the first two requests for prior authorization. The third application resulted in approval for the requested 56 hours on May 27, 1999. However, approval for 56 hours per week of nursing services was granted only for the time period February 16, 1999 through March 15, 1999. For the period of March 16, 1999 through March 29, 1999, Texas Medicaid approved only 50 hours of skilled nursing services; for the period of March 30, 1999 through April 12, 1999, Texas Medicaid approved 45 hours, and for the following two days, April 13, 1999 through April 15, 1999, Texas Medicaid approved only 40 hours of skilled nursing.

111. After this limited authorization was received, Pasos Home Health continued to file requests for prior authorization on Alice's behalf for 56 hours per week of skilled

nursing services. A request was submitted on June 1, 1999, for services between April 16, 1999 and June 15, 1999, but only 40 hours of skilled nursing per week were approved. The denial, received on June 2, 1999, stated that "Documentation submitted does not support the number of hours you requested." Once again, Mrs. K did not receive a copy of the denial. Pasos is currently appealing this decision.

112. The most recent request for prior authorization for services for the period June 16, 1999 to August 15, 1999, was submitted to Texas Medicaid by Pasos Home Health on July 8, 1999.

113. Although 56 hours per week of skilled nursing services were requested, Texas Medicaid again approved only 40 hours per week. The notice was issued on July 8, 1999, and it stated that the documentation did not support the requested number of hours. Mrs. K. did not receive a copy of this notice.

114. Alice's physician has alerted Texas Medicaid that Alice requires 24-hour care and that her foster mother is ill-equipped to provide it on her own, by including an additional letter of need, dated April 26, 1999, with her plan of care.

115. Alice's foster mother does not believe that she can personally care for Alice's needs around-the-clock and fears that she will not be able to continue with Alice's placement in her home if she is expected to do so.

116. The threat to Alice's current foster placement was recognized by the El Paso District County Court. On October 1, 1998, Judge Patricia Macias issued an order approving a permanent foster care arrangement with Alice and her current foster family. To ensure the

success of that arrangement, an additional court order was issued that Alice "be provided with continuous and constant home nursing care for no less than 8 hours a day." Since Medicaid refused to pay for this service, the Child Welfare Board was petitioned and agreed to pay the nursing expenses incurred during that period. Skilled nursing continues to be provided to Alice for 56 hours each week as a result of the court order, but Pasos Home Health has been reimbursed for only a fraction of these services by Medicaid.

117. Without the additional medically necessary nursing services she requires and an assurance that Texas Medicaid will provide coverage, Alice is at risk of losing her foster care placement and being placed in an institution.

Keyaira R.-D.

118. Keyaira R.-D. is five-years-old and lives with her grandmother, Rita D., in Austin, Texas. Ms. D. is managing conservator for Keyaira.

119. Keyaira is a Medicaid beneficiary who has participated in the Medicaid program since 1994.

120. When Keyaira was four-months-old, she sustained a closed head injury, resulting in a fractured skull and a subdural hemorrhage that lead to cerebral edema. As a result, Keyaira is unable to speak and has quadriplegia, a seizure disorder, a vision impairment, history of trachia malaysia causing difficulty swallowing, global developmental delay and gastroesophageal reflux

121. Because of the quadriplegia, Keyaira uses a wheelchair for mobility. She has increased tone in her upper extremities, impacting her range of motion.

122. In order to decrease the likelihood of atrophy to her muscles and to increase her strength, one of Keyaira's treating physicians, Ezam Ghodsi, M.D., prescribed the use of a Mayatek muscle stimulator.

123. The Mayatek muscle stimulator is a piece of durable medical equipment that is used to increase blood flow to the muscles through electric stimulation.

124. Durable medical equipment is a benefit of the Texas Medicaid program.

125. In July 1998, Dr. Ghodsi submitted a request to Texas Medicaid that it fund the cost of the Mayatek muscle stimulator. On July 14, 1998, Texas Medicaid, through NHIC, denied the request.

126. Texas Medicaid did not send notice of this denial to Ms. D.

127. Upon information and belief, Ms. D. did not receive a denial notice because Texas Medicaid never provides notice to beneficiaries when it determines that a service is not a covered benefit of the Medicaid program.

128. Instead, the medical equipment provider, D&L Medical Products, Inc, received a copy of the application it had sent in support of the request for the muscle stimulator and written across the application were the words, "not a benefit of the home health program." This "notice" failed to provide any other information about the basis for the denial of Medicaid coverage of the Mayatek muscle stimulator.

129. Texas Medicaid has also terminated all of Keyaira's nursing services.

130. Keyaira began receiving nursing services in 1994, subsequent to sustaining the closed head injury.